FINAL PROGRESS REPORT

Title of Project: Personalized Engagement Tool for Pediatric BMT Patients and Caregivers

Principal Investigator: Sung Won Choi, M.D., M.S.

Team Members: David Hanauer, M.D., M.S.
Lawrence An, M.D.
Mark Ackerman, Ph.D.
Thomas Braun, Ph.D.
Jim Lepkowski, Ph.D.

Organization: University of Michigan

Project Period: 09/10/2014 - -2/28/2017

Project Officer: Edwin Lomotan

Agency Support: Agency of Healthcare Research and Quality (AHRQ)
Center for Evidence and Practice Improvement (CEPI)
Division of Health Information Technology (Health IT)

Grant Number: R21HS23613

Structured Abstract

Purpose: The objective of this proposal was to: 1) generate understanding of user needs in the development of a personalized HIT tool (BMT Roadmap) for caregivers undergoing blood and marrow transplant (BMT); and 2) conduct a pilot and feasibility study of BMT Roadmap.

Scope: BMT is a major stressful event and impacts physical, psychological, and social well-being. Based on the intense, physically demanding procedure, medically fragile BMT patients remain dependent on caregivers. As such, it is critical that caregivers are informed and involved in the delivery and coordination of care, particularly in the inpatient setting.

Methods: User-centered design techniques were used to develop BMT Roadmap, a web-based IT application on an Apple iPad®, which integrated patient-specific health information from Epic®. It included domains for: laboratory results; medications with plain language summaries; clinical trial summaries and consent documents; health care provider directory; phases of care, and discharge checklist. The study was IRB-approved (IRB HUM00100126) and registered under ClinicalTrials.gov (NCT02409121) to conduct a pilot study of BMT Roadmap in caregivers. Mixed methods data collection were used to examine participant-reported outcomes.

Results: BMT Roadmap was well-received and considered useful. Our qualitative findings suggest that patient-centric HIT tools may be able to engage caregivers in hospital care. To our knowledge, there are no other HIT applications in the market meeting this need and thus the findings herein are novel. The quantitative findings are currently being analyzed and will be integrated with the qualitative findings.

Key Words: HIT, patient-centered care, caregiver, acute care portal, PROs

Purpose

Objectives of the Study: Blood and marrow transplantation (BMT), commonly referred to as hematopoietic cell transplantation (HCT), is a potentially curative therapy for many malignant and non-malignant hematological conditions. Despite advances over the past decade, which have led to improved outcomes, BMT remains an intense treatment modality often requiring prolonged inpatient-based care. The immune system shuts down for months after the procedure, making patients susceptible to life-threatening complications. It is therefore common for BMT patients and caregivers to experience increased risk of financial and emotional burden, hospital readmission, and health service utilization, highlighting the importance of active involvement of BMT patients in their own health care (self-efficacy). For pediatric BMT patients, caregiver activation plays a critical role in effective patient-parent-provider partnership, particularly during the acute phase of BMT. This partnership is increasingly recognized as the optimal model for health care delivery, particularly for those facing life-altering medical decisions. It is essential to develop strategies to enhance this partnership. Health information technology (IT) offers the potential to overcome constraints in health care delivery limited by provider time, complicated health information, and financial pressures. Significant gaps in knowledge exist on use of health IT tools using low-cost and well-accepted delivery platforms in inpatient care to support patient activation. In this proposal, we hypothesized that a tablet-based tool displaying personal health information could provide a platform to promote activation and enhance health communication. The objectives of the study were to:

1. Generate understanding of user needs in the development of a tablet-based Patient-Centric Health IT Tool (BMT Roadmap) caregivers of pediatric patients undergoing BMT.

2. Conduct a pilot and feasibility study of BMT Roadmap in caregivers of patients undergoing BMT.

Scope

Background: BMT (commonly referred to as HCT) is a high-risk medical procedure in which hematopoietic cells from the bone marrow, umbilical cord blood, or peripheral blood of a related or unrelated donor or the patient's own hematopoietic cells are administered to the patient after chemotherapy with or without radiation therapy (conditioning regimen). It is definitive therapy for a wide range of malignant and non-malignant hematological conditions. The average length of hospital stay for patients undergoing BMT is 40 days, characterized by four phases: 1) the conditioning regimen; 2) myelosuppression; 3) deconditioning; and 4) cell count recovery. The conditioning regimen administered during Phase 1 leads to a decline in counts of white blood cells, hemoglobin, and platelets (myelosuppression), increasing the risk of painful mucositis, bleeding complications, organ toxicities, and life-threatening infections (Phase 2). It is not uncommon for BMT patients to require intravenous narcotics and total parenteral nutrition for effective pain and nutrition management, respectively. These therapies contribute to decreased physical activity and deconditioning (Phase 3) until cell count recovery takes place (Phase 4).

Context: Technically complex medical data can create *information asymmetry*. Despite bedside rounds that include parents, providers still have access to all of the clinical data and parents have no access to pertinent data. Currently, bedside rounds occur in the early morning when parents are generally still asleep. Parents ask questions only when they are informed, empowered, and have the confidence. Information sought by parents during the rapid pace of bedside rounds is typically hand-written on loose sheets of paper. It is time-consuming and cumbersome to continually ask the health care team to print out daily results of blood tests or lists of medications. The pace, complexity, and intensity of inpatient care is further impacted by rotations with different providers. However, a new health care delivery model is emerging that is patient-centered. It is critical that we are responsive to the growing needs of health care to promote safe, effective, patient-centered, timely, efficient, and equitable practices. Research in patient-centered care addressing the complex BMT population is necessary.

Setting: AHRQ's "Findings and Lessons from the Improving Management of Individuals with Complex Healthcare Needs through Health IT Grant Initiative" demonstrated overall progress in health IT use in patients with complex health care needs in the ambulatory care setting. Positive impact was seen by the improved flow of information as patients transitioned between clinicians and high levels of patient engagement in self-care. However, there are gaps in development of health IT applications for patients in hospital-based care settings. The vast majority of available health IT applications that serve to bridge the gap between patients and providers have been in the outpatient setting through portals, which have been shown to enhance communication, increase overall satisfaction with care, expand access to health information, improve disease management, and positively impact patient outcomes. While patients have rights to access their clinical information, there is lack of knowledge regarding experiences and preferences of providing such access and mechanisms of how that contributes to outcomes. Therefore, in this proposal, we examined the use of a patient-centric health IT tool in the acute, inpatient setting.

Participants: Greater emphasis on earlier hospital discharges and burden shift of self-management falling heavily on patients and their caregivers without providing adequate information and instructions increase the risk for medical errors and disease-specific complications. There are also growing expectations for providing quality care and paying more attention to patient-centered care by health care providers. This intersection provides the opportunity to test novel interventions to support patient-care related activities, particularly in patient populations with complex medical conditions and with high information needs, such as pediatric BMT patients who *partner with parents in the co-management of their care*. Studies in self-efficacy and health management behaviors of parents have been associated with positive health outcomes for patients and caregivers. Therefore, it is strongly desired to support these efforts of self-efficacy and self-management. The literature suggests that BMT patients experience significant distress at the time of discharge and effective strategies designed to better prepare and transition patients to self-manage their disease conditions from the inpatient to outpatient settings have been underdeveloped. Therefore, in the original grant application, we proposed to examine the use of BMT Roadmap in caregivers of pediatric patients. However, based on the reviewers' comments, we also included pediatric patients in the clinical research studied. Moreover, in Year 2 of the grant, to further implement and disseminate our research findings, we expanded the study to adult BMT patients and caregivers.

Results

Principal Findings:

1. Based on a series of qualitative studies on caregivers at our BMT Unit, we detailed the caregiving practices of caregivers (particularly parents) and how we might help them in their information tasks by developing a patient-centric health IT tool, specifically for the inpatient setting. BMT, and especially pediatric BMT, is of considerable interest not only because the care process is so complex and difficult, but also because it offers an examination of future healthcare issues. A growing number of specialized treatments are being developed, and patients and families (or in this case, parents and families), need to understand the implications of those treatments quickly and effectively. BMT differs from what is typically understood as chronic care in important ways – such as the amount of resources involved, including clinician time – but it is similar in that much of the work that BMT caregivers perform requires them to collaborate closely with a team of healthcare professionals, learning the specialized language and the technical practices of medicine.[1]
2. Clinical information work includes tasks such as learning how to perform medical procedures like line work, understanding and organizing medication regimens, tracking a child's diet, fluid intake, exercise, and bowel movements, interpreting blood counts, researching treatment options and medication side effects, and becoming adapt at conversing with and questioning medical professionals.[2]
3. Three stages of the caregiving experience were identified that could potentially be addressed by technology to support and improve engagement: a) institutional scaffolding and navigating the health system; b) managing day-to-day tasks of caretaking; and c) transitioning to outpatient management.[2]
4. A *proof-of-concept* health IT tool (BMT Roadmap) was developed to meet the information needs of BMT patients and caregivers that provided *real-time* access to: a) laboratory results; b) the patient's clinical trials; c) care team names and photos; d) discharge checklists with central line care videos; and 3) informed consent documents.[3,4]
5. BMT patients and caregivers value being active participants in their health care. They support participation in evidence-based research that potentially improves health care outcomes for future patients. They support the use of technology to support the informed consent process.[5-7]
6. Despite being a relatively heterogeneous population of caregivers, BMT Roadmap was well-received and considered a useful tool. Caregivers suggested improvements for adding more information to the tool, including daily check lists for tasks such as walking and bathing as well being allowed to use the tool in the outpatient setting or upon readmission.[8]

Outcomes:

7. In the pilot study, 10 caregivers participated in the study: 80% female, 90% white, median age 36 years (25-54 years). Transplants were 50% autologous and 50% allogeneic. Median time of use was 104.1 minutes (6.4-256.2 minutes) over 29.5 days (21-68 days). Minutes used and days used were strongly inter-correlated (r=.90, p=0.001) and correlated with inpatient days (r=.70, p=0.05; and r=.81, p=0.01 respectively). The most time spent was in the laboratory module, followed by health care provider directory, medication, and phases of care modules (Table 1). Quantitative survey results showed that trait anxiety (STAI-T) was decreased, caregiver quality of life (CQOL) was improved, and caregiver activation (C-PAM) was increased at discharge compared with baseline (Table 2). The highest level of self-rated activation, as assessed by the C-PAM survey increased from 40% (admission) to 50% (discharge), and reached 85.7% (day 100). Total C-PAM score showed a strong trend toward increased activation from admission to day 100 (p=0.08). Caregivers with higher engagement had less trait anxiety at day 100 (r=.82, p=0.02), but engagement was unrelated to minutes of iPad use, days of iPad use, inpatient days, and caregiver quality of life. Caregivers described the iPad as easy to use and all used it for some portion of their stay (Table 3).[10,11] We are preparing the full analyses to submit a mixed methods-based manuscript on the use of BMT Roadmap in the inpatient setting, describing both pediatric patient and caregiver experience and outcomes – qualitative and quantitative findings.
8. Based on the exciting preliminary findings in the pediatric BMT population, we have expanded the IRB-approved study in the adult BMT population. The findings in adult patients and caregivers have been presented at two different international/national conferences.[12,13] Twenty HCT patients undergoing first-time allogeneic HCT enrolled in the study between January – June 2016. As shown in Table 4, the mean age of participants was 53 years (range 27 – 71 years). The sample was predominantly male

(N=15) and white/Caucasian (N=18), and had at least a high school diploma or higher education (N=16). The indication for HCT was malignancy. The majority had an intermediate-high-risk HCT-comorbidity index (N=14), and received an unrelated donor HCT (N=11) from PBSC donors (N=14). Eleven participants completed all of the PROMs at each time point. Two patients declined further participation prior to discharge. Three patients died between discharge and day 100 post-HCT due to complications of graft-versus-host disease. The mean hospital stay was 23.3 days (17-37 days), and patients had access to BMT Roadmap for a mean of 21.3 days (15-37 days). The total time spent on BMT Roadmap ranged from 0-139 minutes per patient with a mean of 55 minutes (SD = 47.6). Patients logged in at least once per day for a mean number of 7.6 days (SD = 6.3). Patients spent majority of the time in the laboratory module, followed by phases of care and then medications. The least utilized module was the discharge checklist (Table 5).

9. *Adult BMT Patient PROMs: Perceived Usefulness (PU) and Perceived Ease of Use (PEU):* Both PU and PEU showed high internal consistency (Cronbach's alpha = 0.98). PU and PEU did not change from baseline to discharge to day 100 post-HCT (Table 6).
10. *Adult BMT Patient Activation:* We measured activation (PAM) and found that PAM scores increased from baseline to discharge and to day 100 (Table 4)**.** Activation scores did not correlate significantly with total time used (r = -0.26). At day 100, activation was inversely related to length of stay (i.e., lower PAM score trended with longer length of stay; PAM and total utilization r=-0.52, p=.055). Among the 11 participants who completed the PAM at all three time points, repeated measures ANOVA showed that activation significantly increased over time with scores of 67.6 (*SD*=16.65) at baseline, 72.8 (*SD*=13.62) at discharge, and 77.7 (*SD*=19.85) at day 100, (F= 5.64; p=0.04). We then explored activation relative to use. The intermediate users showed a trend toward increased activation versus the lowest and highest utilizers at discharge and day 100 (F = 3.52, p = .06; and F = 3.62, p = .06 respectively).
11. *Adult BMT Patient Psychological PROMs:* Measures of depression (POMS-depression), anxiety (Trait and State), and distress (POMS-Total, CTXD, and IES) were assessed to determine the effects of potential confounders on utilization and/or activation. We found that use was not significantly correlated with any of the psychological measures at any of the time points, suggesting that these measures did not confound utilization. However, the measures themselves were intercorrelated (Table 7). Notably, at discharge, depression correlated positively with state anxiety (r = .81, p = .000) and trait anxiety (r = .71, p = .001). Similar relationships were apparent at day 100 post-HCT (Table 7).
12. *Adult BMT Patient Activation* was not associated with any of the psychological PROMs at baseline or day 100 (i.e., the two time points that represent time periods of no BMT Roadmap use). Interestingly, at discharge, activation correlated significantly and negatively with depression (r = -0.52, p = 0.04), trait anxiety (r = -0.50 p = 0.05) and state anxiety (r = -0.59, p = 0.02), suggesting that greater activation was associated with less depression and anxiety.
13. *Adult BMT Patient Depression and distress*, as indicated by the IES-R decreased significantly from baseline to discharge to day 100 post-HCT (F = 7.83, p = 0 .01 and (F = 5.36, p = 0.02, respectively).
14. *Adult BMT Patient Age, length of stay, and cell dose* were not correlated with any psychological PROMs at any time point. However, more educated patients showed more state anxiety at baseline and discharge (r = 0.62, p = 0.01; r = 0.54, p = 0.03 respectively). In addition, at discharge the more educated were more depressed (r = 0.62; p = 0.01) and exhibited a trend toward more overall emotional distress (POMS-T r = 0.47; p = 0.07). By day 100, education was not correlated with any of the psychological PROMs.

Discussion

There is a growing expectation that safe health care across the continuum must be organized using patient-centered systems. To achieve this, an integrated, multi-disciplinary approach is needed to facilitate patient communication, collaboration, and efficiency. Indeed, based on user-centered design techniques, a multidisciplinary team developed a novel health IT tool for adult HCT patients to use during their hospital admission. The present study was feasible to recruit and enroll patients. We examined the views and perspectives of participants interacting with BMT Roadmap through qualitative and quantitative PROs. An important finding of our work was that patient activation increased across time (i.e., baseline, discharge, and through day 100) in both pediatric and adult BMT populations. To our knowledge, this is the first report of HCT patients interacting with a personalized health IT tool during their transplant admission.

We recently submitted a review manuscript to describe the implementation of acute care patient portals and recommendations on the utility and use from six early adopters.[9] Emerging data suggests that widespread use of portals will improve patient safety. Given the urgent need to reduce medical errors and the patient's promising potential role in preventing them, an explicit portal feature devoted to safety is justifiable. Ideally, the portal's safety feature encourages patients to participate in their safety plan, and highlights specific, actionable steps that patients can take to improve their own safety. Future studies should determine whether patient reporting of safety concerns through portals or other personalized health records mitigates potential safety incidents, and describe how patients perceive safety threats. Potential additional safety-oriented content includes: (1) reporting adverse events, such as worsening symptoms or medication side effects, (2) verification of contact names and numbers in case of emergency, (3) wishes and information related to resuscitation and emergency care, and (4) medication review.

Emerging consensus, as shown in the work from this grant proposal, acute care portals (such as, BMT Roadmap) must engage patients' caregivers as well as patients themselves. This is especially true regarding surrogate decision makers for pediatric patients. Caregivers will not only benefit from better access to information, but can contribute detailed information to improve quality of care, as was described in our findings herein. Unlike patients, most caregivers are not in the hospital for the entire hospitalization or may even switch caregivers. Therefore, home access would keep caregivers informed and reduce the anxiety of not being present. Home access will become more feasible when institutions offer portal access on personal devices, in addition to hospital-provided devices. A videoconferencing feature could potentially help patients connect with their caregivers outside of the hospital setting.[9]

In our single institution experience, patients and caregivers readily participated in sharing PROs through the BMT Roadmap health IT platform. Lessons learned and recommendations for future directions include continued attention to patient privacy, but also ensuring that technological flaws are handled in real-time. Patients and caregivers described "signing-in" to multiple devices with different passwords remains an issue, or if connection to the secure hospital network failed – often causing frustration. Nonetheless, in future work, we plan to expand PRO data capture on our electronic platform. In efforts to build this system for ambulatory care settings and/or home care settings (maintain of self-management), capturing PRO data in between clinic visits will be critical.

Conclusions

Our research reported herein has been based on a step-wise approach to studying patient safety in a vulnerable population. First, we examined complex information needs from patient-caregiver perspectives. Second, our observations formed the basis of an AHRQ R21-funded *proof-of-concept* health IT tool in the inpatient setting. Implementing BMT Roadmap in both pediatric and adult BMT settings was safe and feasible. There were no patient privacy or safety concerns. Participants readily shared PRO data capture on BMT Roadmap. In future work, we propose to expand this tool to the home / outpatient setting, thereby broadening the scope of its applicability to care across the continuum. A recent systematic review suggests that there are few patient-centered health IT tools in the outpatient setting, specifically tools that target and improve patient safety, potentially through PRO data capture. Our goal is to shift current practice with a health IT platform that provides better information access to *patients and caregivers* and harness the benefits of evidence-based patient safety practices (bundles and checklists). Our study was limited by its non-randomized study design and single institution experience. It is important to expand this study in a multi-center, randomized study design

Significance

Health IT applications that integrate with the existing electronic health record (EHR) and present information in a condensed, user-friendly format could improve coordination of care and communication. Because patients have varied levels of activation, different cultural backgrounds, disparate technological skills, and varying familiarity with the health care system, an intuitive health IT application designed with content using plain language may provide sufficient informational needs to support activation. Nonetheless, prior to widespread adoption, complex interventions should be developed systematically with appropriate methodological design and testing to ensure usefulness, adoption, and sustainability. In our study, user-centered design techniques,

including key stakeholders (i.e., patients, caregivers, health care providers), led to the development of a novel patient-centric health IT tool that was user-friendly and easy-to-use. Implementation and dissemination of our research has been made through presentations at national conferences and productive publications in peer-reviewed manuscripts. After implementing the study in pediatric BMT, we then implemented the same health IT tool (BMT Roadmap) in adult BMT. Patients and caregivers readily accepted the technology and interacted with the system, as shown in the data above. Patient-reported outcome data capture on a health IT platform (BMT Roadmap) remains a significant finding from our work – the safety, feasibility, and acceptance from the patients. Additional modules are also being developed based on qualitative data feedback from patients and families. We are designing low-fidelity prototypes for patients/caregivers and providers to begin implementation and real-time data output for patients-providers to share decisions and better communicate symptom management (Figures 8-10).

Implications

BMT Roadmap was developed with a multi-disciplinary team to address multiple information needs of caregivers undergoing HCT. Our study suggests that patient-centric HIT tools may be able to engage caregivers in hospital care. BMT Roadmap could meet this need, particularly in the HCT setting where complex, long-term communication and information recall is necessary for both patients and caregivers. To our knowledge, there are no other HIT applications in the market meeting this need and thus the findings herein are novel and of relevance. Nonetheless, we recognize the limitation of our small sample size and the single institution experience from this proposal. We are expanding the current technology to an adult BMT population, and have included quantitative assessments to integrate the findings with our qualitative domains. It remains essential that evidence-based data with user-centered experiences are captured before widespread dissemination of such tools. This study filled a gap in our existing knowledge. In future work, we will leverage and build upon our prior work in the inpatient setting to expand our existing health IT tool to the outpatient setting, across the care continuum. We hope to build on our AHRQ R21 project to generate new knowledge regarding the role of patient-caregiver behaviors, patient-provider interactions, and health care system and community engagement in ensuring patient safety in the ambulatory care setting. Our findings suggest that patient safety may be improved with personalized health IT tools. It will be critical to further scale and spread the use of such health IT tools to support PROs between patient-caregiver-providers.

Ideal educational content is disease-specific, tailored to age and health literacy level, and not so dense as to be overwhelming. Unfortunately, such content is not always easily available or developed. BMT Roadmap was created with easy-to-read educational materials for common transplant medications. While locally developing the content ensured readability and appropriateness, developing such content for all possible medications is not feasible. One solution is to offer a broader variety of endorsed content, for the patient to choose between based on their preferences. In the future, patient education through acute care portals or applications like BMT Roadmap should aim to help patients assume responsibility for care after discharge, supplement provider-based education, and lessen patients' uncertainty about their condition. Targeted strategies to achieve these goals require further consideration and evaluation. One potential strategy is to better integrate education with medical record viewing, such as pop-ups that define medical terms. Another potential strategy is to provide access to trusted online communities or electronic meetups, where patients can learn from more experienced patients.[9]

Table 1 -- Quantitative Analysis of Features Used with Tablet-Based Caregiver Engagement Tool: Implications for Future Designs

Patient ID	Days *with* iPad	Days *using* iPad	Total (min)	Labs (min)	Medications (min)	Directory (min)	Phases (min)	Discharge Checklist (min)	Videos (min)
1	58	54	256.2	172.9	26.00	15.73	8.88	0.68	3.25
2	21	2	6.43	0.25	1.72	2.25	0	0	0
3	22	21	123.4	60.02	4.50	11.88	7.85	0.05	10.95
4	29	14	50.12	10.73	3.57	3.17	11.58	2.02	0
5	30	10	105.8	33.00	17.53	15.93	15.52	0.22	0
6	24	22	102.5	67.40	5.12	13.95	3.25	0	0
7	31	7	17.80	7.28	0.62	4.72	3.40	0	0
8	29	25	51.73	22.67	1.85	12.57	7.60	0.95	0
9	35	25	110.2	41.23	16.83	4.95	11.20	2.77	14.78
10	68	41	153.3	44.15	11.48	16.43	16.50	0.48	8.35

Total minutes refers to the total time spent using any component of the BMT Roadmap. Each subsequent column represents the total time, in minutes, using the various domains within the BMT Roadmap.

Table 2 --Quantitative Survey Results			
Survey Measure	*Admission* N=10	*Discharge* N=10	*Day 100* N=7
C-PAM	67.85	72.58	80.90
STAI-Trait	-0.06	-0.59	-0.76
STAI-State	0.81	-0.03	-0.64
CQOL	43.50	36.50	40.00
POMS - Total	48.00	45.00*	49.00
POMS - Depression	42.50	42.50	43.00

All data represents medians.

*N=9, patient did not complete POMS survey fully

C-PAM=caregiver patient activation measure; higher scores represent more activation.

STAI=State-Trait Anxiety Inventory; higher scores represent more symptoms

CQOL=Caregiver Quality of Life; higher scores represent worse QOL

POMS=Profile of Moods; higher scores represent more symptoms

Table 3. Representative Participant Responses from Qualitative Interviews about the BMT Roadmap

Usefulness, ease-of-use, and likeability	Laboratory domain was the most viewed	Desire for additional domains and expansion into the outpatient setting
"…at the beginning phase, whenever you start a phase of treatment or whenever you encounter something out of the ordinary, you want information. That's why the app is so nice. It's all organized really correctly."	"I like that you can see the electrolytes in the liver, because that's not something I've really had any experience with looking at. Before they would just reach, 'Oh, this, this, and this are at this level,' and you never knew if that was good or bad."	"Maybe it would have your exercise box, because she writes down everything that she eats at night. Why not bake that into this thing? And if they made it so, like she said, a doctor can look in and see."
"I've noticed that this tool has made me a lot better at understanding her care, so I love it."	"I think the labs feature is really nice. Especially for a parent who has done this for a long time."	"To turn this into an app would be incredible." "[Not taking it home] just kills the sustainability of the whole project."
"I remember that one particular patient that I had to redirect a lot also. She, for example, would be… Maybe not, during the times we were working. She is sleeping. She doesn't want to engage. She doesn't want to wake up. To have this, to be able to be a good tool, to have this later, at a time that she is more receptive or things like that. Having it as a tool that they can go to at any time, is very helpful."	"I actually picked it up today because I didn't want to bug [our nurse] just for count numbers, so I pulled the labs up when I got back in. If I miss rounds I'll pull them up, or if they haven't been written up there yet. That's just convenient to check them, because now that his counts are coming in, I can go in there real quick and check and see if we're up, if or what's going on."	"The other thing with the checklist maybe have another checklist where it's like, "Okay what are the activities for today?" And the nurse creates with the patient their checklist for the day. Today we're going to learn how to do the dressing change. Today we're going to learn more about these meds. Today we're going to learn more about your CBC count or bathing."
"I think it [BMT Roadmap] would because it would give us cues, too. It would help us remember the things that they need. So I think it would do nothing but improve what they go home with. What they take away."	"I think it [BMT Roadmap] helps so you can see [laboratory result] trends. I think any time that we have a visual aid like this, especially when it's this simplified, I think that really helps."	"If you can send emails to the nurse practitioner person. That wouldn't have to be real time; but if I have a question, instead of calling some 1-800 number, just shoot it right in there."
"I liked it. I liked it all. I felt that it was helpful. I was going to show it to her dad when he came down, because he always asks questions that I can just have him read it."	"From my perspective as far of keeping up to date of what her counts are, while that [rounds] seems like an okay process from my end, she is often asleep. So, she doesn't know. I think she will appreciate later as she gets into having that information accessible."	"As parents they're going to need some hardcopies to take home unless they were to have this program that they could have on their computer like an application, which may be coming in the future. That would be great."

Table 4: Adult Patient Demographic and medical variables

	M (SD)	Range	*N* (%)
Age	52.65 (12.76)	27 -71	
Gender			
Female			5 (25%)
Male			15 (75%)
Race			
White, non-Hispanic			18 (90%)
Black or African American			1 (5%)
Hispanic or Latinx			1 (5%)
Education			
High school diploma or GED			6 (30%)
Some college or trade school			4 (20%)
Bachelor's degree			2 (10%)
Graduate degree			4 (20%)
Missing			4 (20%)
Medical variables			
Cell Dose	4.82 (2.42)	1.3-8.4	
Length of stay	23.3 (5.00)	17-37	
Indication for BMT			
Leukemia			10 (50%)
Lymphoma			4 (20%)
MDS			5 (25%)
Multiple Myeloma			1 (5%)
Donor			
Unrelated			9 (45%)
Related			11 (55%)
CI			
Low			6 (30%)
Intermediate			6 (30%)
High			8 (40%)
Cell source			
PBSC			14 (70%)
BM			6 (30%)
HLA Matched			
No			1(5%)
Yes			19(95%)

Table 5. Adult Patient Utilization

	Minimum	Maximum	Mean	Standard Deviation
General Usage:				
Total Usage Time (minutes)	0.0	138.8	55.0	47.6
Number of Days between First and Last Login, Inclusive	1.0	28.0	14.5	8.3
Number of Days the User Logged in at Least Once	1.0	22.0	7.6	6.3
Module Usage (minutes):				
Laboratory results	0.0	44.5	13.5	12.5
Phases of care	0.0	32.7	10.3	9.3
Medications	0.0	26.5	7.9	7.9
Care team directory	0.0	16.2	5.4	5.3
Discharge checklist	0.0	5.2	0.7	1.4

Table 6. Adult Patient-Reported Outcomes Measures (PROMs)

	M (SD)	Range	*N*
Perceived Usefulness[a]			
Baseline	3.12 (1.63)	1-7	15
Discharge	3.03 (2.10)	1-7	17
Day 100	3.23 (2.20)	1-7	14
Perceived Ease of Use[a]			
Baseline	2.01 (1.08)	1- 4.5	15
Discharge	2.29 (2.12)	1-7	17
Day 100	2.87 (2.11)	1-7	14
Activation[a]			
Baseline	64.93 (15.01)	48.9 - 100	15
Discharge	72.13 (11.76)	51 -90.7	16
Day 100	77.53 (18.90)	13.7-100	14
Depression[b]			
Baseline	45.11 (5.87)	40-62	19
Discharge	41.88 (2.91)	40-51	17
Day 100	41.78 (3.07)	40-50	14
Anxiety-Trait[b]			
Baseline	.03 (1.14)	-1.45 – 2.95	19
Discharge	-.23 (1.01)	-1.56 -1.48	17
Day 100	-.47 (1.06)	-1.56 – 2.39	14
Anxiety-State[b]			
Baseline	.07 (1.18)	-1.4 – 3.34	19
Discharge	-.48 (0.87)	-1.42 – 1.01	17
Day 100	-.63 (1.06)	-1.52 - 1.40	14
Distress: POMS Total[b]			
Baseline	48.79 (10.61)	36-74	19
Discharge	45.59 (6.66)	36-56	17
Day 100	43.71 (6.41)	35-56	14

Distress: IES-R[b]			
Baseline	41.43 (13.39)	26-65	14
Discharge	32.13 (7.42)	22-50	15
Day 100	28.85 (5.14)	22-37	14
Quality of life CTXD[b]			
Baseline	1.08 (.49)	.32- 1.82	15
Discharge	.73 (.50)	.07- 1.74	16
Day 100	.59 (.50)	.04 -1.82	14

[a]Higher score is more desirable; [b]Lower score is more desirable

Note. 11 patients completed the PAM at all 3 time points; 5 patients did not complete all PROMs at baseline due to technical error.

Table 7. Intercorrelation Matrix of PROMs Over Time

TIME 1 (n=15-19)	POMS	PAM	CTXD	IES	State	Trait
POMS		-.338	.755**	.258	.844**	.880**
PAM			-.346	-.034	-.486	-.477
CTXD				.581*	.660**	.679**
IES					.190	.174
State						.888**

TIME 2 (n=16-17)	POMS	PAM	CTXD	IES	State	Trait
POMS		-.461	.585**	.370	.819**	.688**
PAM			.230	-.202	-.538*	-.522*
CTXD				.581*	.636**	.695**
IES					.355	.448
State						.936**

TIME 3 (n=14)	POMS	PAM	CTXD	IES	State	Trait
POMS		-. 388	.445	.449	.895 **	. 747**
PAM			-.260	-.098	-.197	-.200
CTXD				. 763**	. 672**	.757 **
IES					.621*	.655*
State						.852 **

Time 1=Baseline; Time 2=Discharge; Time 3=Day 100 post-HCT

* p=.05; ** p=.01, p=.001

Figure 1: Administrator PRO View

The manage tab provides functions that would enable the admin to look for a specific patient data using the medical ID privided to them on the record and take required actions.

Actions supported :

1) deleting a patient record
2) Archiving inactive patient data.
3) Auto archiving of old patient data.

The export feature allows the admin to eport patient data in different formats as required that can be imported to other platforms either for research or to integrate with EMR

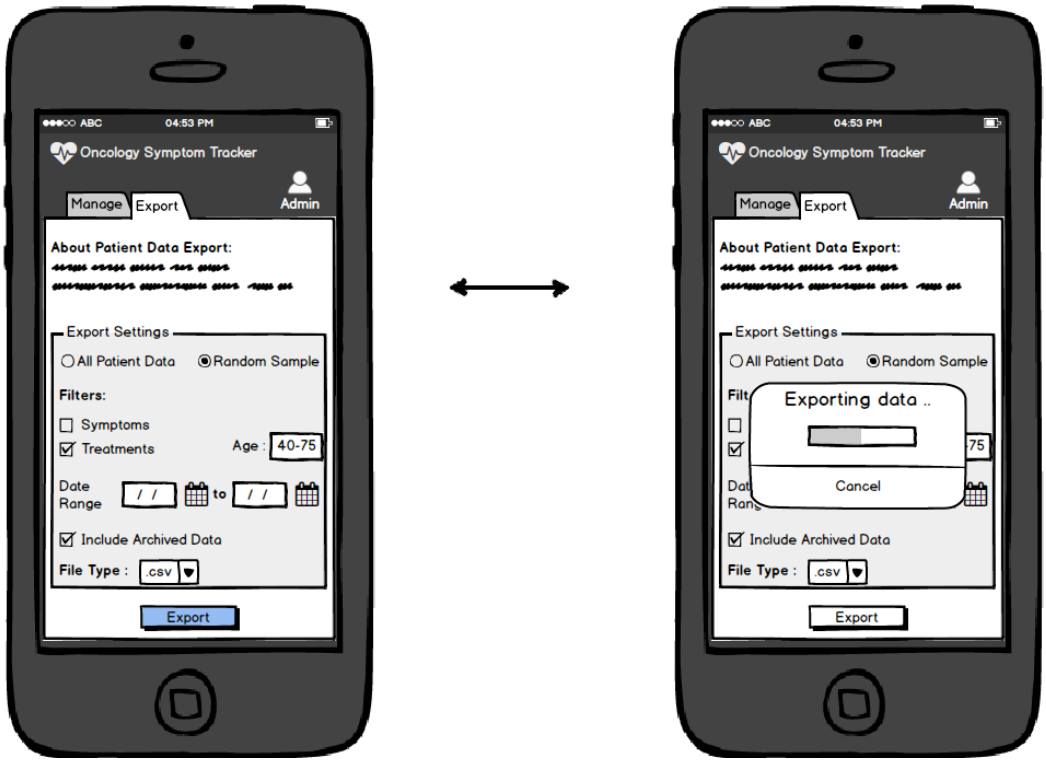


Figure 2: Health Care Provider PRO View

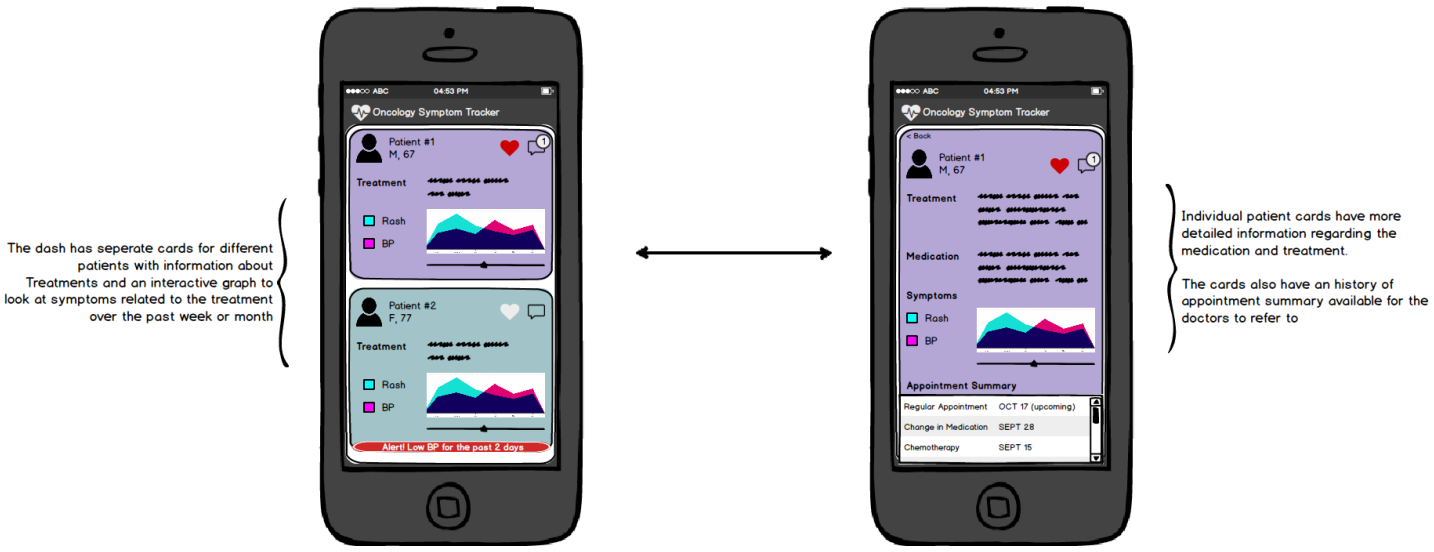
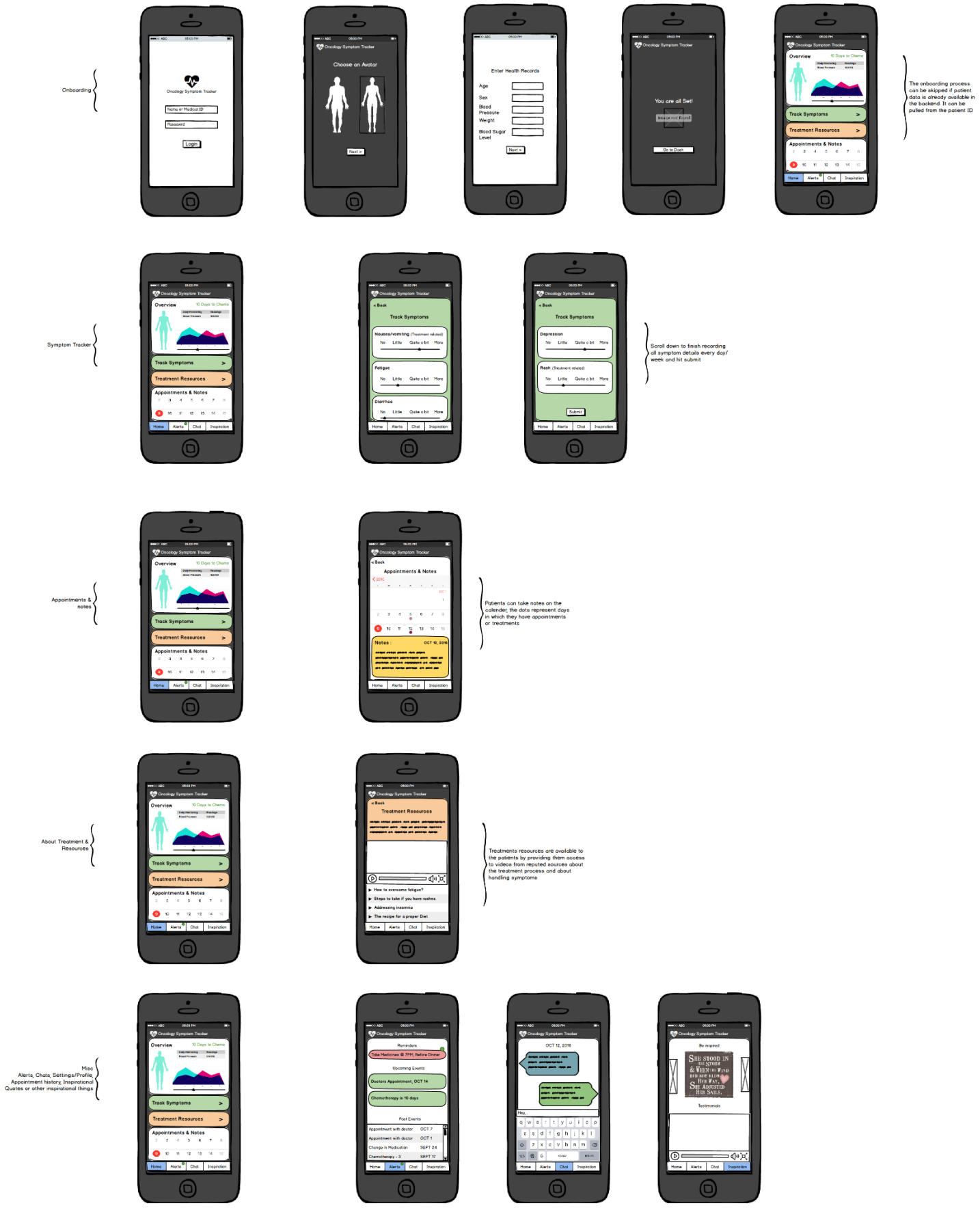


Figure 3: Participant PRO View



List of Publications and Products

Conference Paper

1. Kaziunas E, Buyuktur A, Jones J, et al. Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers. In: Proceedings of the ACM 2015 Conference on Computer Supported Cooperative Work (CSCW '15); 2015 Mar 14-18; Vancouver, BC, Canada.

Journal Papers

2. Kaziunas E, Hanauer DA, Ackerman M, et al. Identifying unmet information needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. J Am Med Inform Assoc 2016 Jan;23(1):94-104. PMID:26510878.

3. Maher M, Hanauer DA, Kaziunas E, et al. A pilot study of a novel health information technology communication system to increase caregiver activation in the context of hospital-based pediatric hematopoietic cell transplantation. JMIR Research Protoc 2015 Oct;4(4):e119. PMID: 26508379.

4. Maher M, Kaziunas E, Ackerman M, et al. User-centered Design Groups to engage patients and caregivers with a personalized health IT tool. Biol Blood Marrow Transplant 2016 Feb;22(2):349-58. PMID: 26343948.

5. Platt J, Thiel DB, Kardia SLR, et al. Innovating consent for pediatric HCT patients. Bone Marrow Transplant 2016 Jun;51(6):885-8. PMID: 26926228.

6. Raj M, Choi SW, Platt J. A qualitative exploration of the informed consent process in hematopoietic cell transplantation clinical research and opportunities for improvement. Bone Marrow Transplant 2017 Feb; 52(2):292-98. PMID: 27748736.

7. Raj M, Choi SW, Platt J. Informed Consent in Hematopoietic Cell Transplantation. Submitted and under review. 2017.

8. Runaas L, Hanauer D, Maher M, et al. BMT Roadmap: A User-Centered Design Health Information Technology Tool to Promote Patient-Centered Care in Pediatric HCT. Biol Blood Marrow Transplant 2017 May23(5):813-19. PMID: 28132870.

9. Grossman LV, Choi SW, Collins S, et al. Implementation of Acute Care Patient Portals: Recommendations on Utility and Use from Six Early Adopters. Submitted and under review. 2017.

Conference Presentation

10. Fauer A, Munaco A, Sankaran R, et al. Patient and caregiver engagement in a health information technology tool in the context of hematopoietic cell transplantation [abstract]**. In: 2016 Healthcare Engineering and Patient Safety Symposium; 2016 Sept 26; Ann Arbor, MI.
    **Poster received symposium Best Poster Award

11. Runaas L, Bischoff E, Hoodin F, et al. A novel health informatics tool to improve caregiver activation: Findings from pediatric BMT in a Hospital-Based Setting [abstract]. Lowenberg, B, ed. American Society of Hematology Annual Meeting; 2016 Dec 2-6; San Diego, CA. Blood 2016 Dec;128:2382.

12. Runaas L, Hoodin F, Kentor R, et al. User-centered design and development of a personalized mobile health application for adult HCT patients in the inpatient setting [abstract]. Tandem Annual Meeting; 2017 Feb 22-26; Orlando, FL. Biol Blood Marrow Transplant 2017 Mar;23(3):S419-20.

13. Fauer A, Runaas L, Churray T, Bischoff E, Hoang T, Gupta R, Van Hentenryck M, Sankaran R, Munaco A, Choi SW. User-centered health information technology tool for blood and marrow transplant patients: A qualitative study. Academy Health Annual Meeting; 2017 Jun 25-27; New Orleans, LA.